S Montana Families
615.994 Living with cancer
M41mfl
1991

MONTANA FAMILIES LIVING WITH CANCER

STATE DOCUMENTS COLLECTION

PLEASE RETURN MAR 23 1992

MONTANA STATE LIBRARY
1515 E. 6th AVE.
HELENA, MONTANA 59620

MONTANA STATE LIBRARY
S 616.994 M41mfL 1991 c.1
Montana families living with cancer /
3 0864 00075066 4

Cover Picture: View of
Tayabeshockup Road and
Gallatin National Forest from
Story Hill, Bozeman, MT

Photo: Wayne Scherr

Design: Bruce R. Eng,
University Graphic Arts,
Montana State Universiy

Andrus Project

Montana Families Living with Cancer

Lloyd D. Bender
Clarann Weinert, S.C.
Lee G. Faulkner
Ruth B. Quimby

College of Nursing,
Montana State University
Bozeman, MT 59717

AARP
Andrus Project

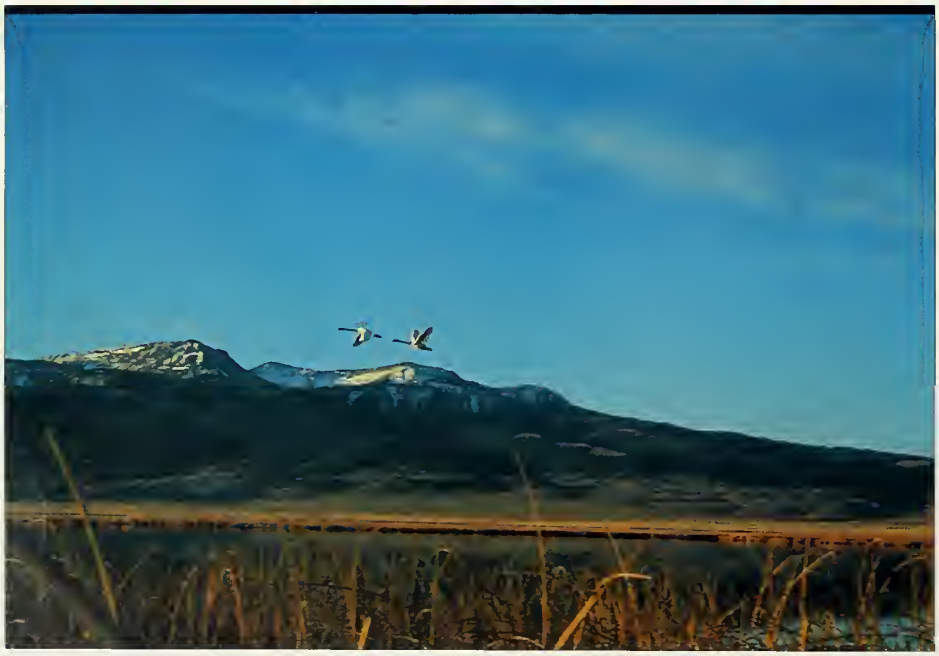
ACKNOWLEDGMENTS

The American Association of Retired Persons Andrus Foundation generously granted funds for the analysis, writing, and publication of this monograph. Appreciation is expressed to the Board of Trustees, Dr. Kenneth G. Cook, Administrator, and Ms. Mary Louise Luna who served as liaison officer of the Foundation to the project. Appreciation also is expressed to the College of Nursing and the College of Letters and Science at Montana State University, Bozeman, for their support.

The data for this report were originally collected by the Montana Family Cancer Project, Montana State University, and funded by the National Institutes of Health, National Cancer Institute (1RO1CA46330). These data would not have been available for this secondary analysis without the untiring efforts of the supporting staff members of the Montana Family Cancer Project. The Montana Family Cancer Project Advisory Committee provided valuable advice and sustaining support to the project staff.

Special thanks go to the many people who voluntarily enrolled in the project and provided data through telephone interviews and mail questionnaires. These people contributed in the hope that their information would benefit society, but aware that it would be of little direct benefit to themselves. Participants became aware of and enrolled in the project through the cooperation and individual efforts of a great many people and organizations throughout the state, including oncologists, other physicians, cancer treatment centers, hospitals, home health care agencies, hospices, the American Cancer Society, television and radio stations, and newspapers.

Particular debts of gratitude are owed to Rodney Fulton for his editing and insightful feedback, and to Sandra Harris and Linda Todd for their diligence in manuscript preparation ■



Montana Dept. of Commerce, J.G. King

AARP

Andrus Project

TABLE OF CONTENTS

EXECUTIVE SUMMARY ____ 2

INTRODUCTION: Families Living With Cancer ____ 4

CANCER IN MONTANA: The Study Families ____ 6

BARRIERS TO CANCER CARE:
Availability and Accessibility of Health Care Services ____ 10
- Availability of Services
- Accessibility to Services

BARRIERS TO CANCER CARE:
Health and Employment of Caregivers and Family Finances ____ 14
- Health Problems of Caregivers
- Employment of Caregivers
- Family Finances

CANCER CARE: Needs of Individuals With Cancer ____ 16
- Care Levels
- Other Health Problems
- Sources of Assistance
- Assistance Needed for Daily Living
- Special Needs of Those with Cancer

CANCER CARE: Assistance Provided ____ 22
- Assistance Caregivers Provided
- Overall Social Support
- Satisfaction with Health Care Professionals

EFFECTS OF LIVING WITH CANCER: Family Life ____ 24
- Depression Among Individuals with Cancer and Their Caregivers
- Family Relationships
- Coping Strategies

DISCUSSION AND STUDY RECOMMENDATIONS:
Options for Improving Cancer Care ____ 28
- Summary of Technical Findings
- Recommendations
- Alternative Methods of Delivering Assistance

LITERATURE CITED ____ 34

SELECTED RESOURCES ____ 35

LIST OF FIGURES

Figure 1 ____ 7
Age of respondents

Figure 2 ____ 7
Education of respondents

Figure 3 ____ 8
Cancer sites: United States, Montana, and study respondents, 1990

Figure 4 ____ 8
Years since diagnosis: Person with cancer

Figure 5 ____ 11
Montana county and city populations and cancer treatment center locations

Figure 6 ____ 12
Average miles to cancer services

Figure 7 ____ 16
Financial and insurance concerns: Person with cancer

Figure 8 ____ 19
Care level: Person with cancer

Figure 9 ____ 21
Expressed needs: Person with cancer

Figure 10 ____ 22
Assistance provided: Family caregiver

Figure 11 ____ 23
Feelings of responsibility and concern: Family caregiver

Most states are searching for solutions to health care for people living in rural regions.

This report presents a graphic picture of the problems faced by families who live with cancer. The analysis recognizes the experiences of these families and the deep emotions generated by these experiences as expressed by individuals with cancer and their family caregivers.

Nearly 154,000 Montana families will be touched by cancer during their lifetimes. However, rural Montana families currently face barriers to health care services which complicate the treatment of illnesses including cancer. For example, distances traveled for cancer diagnosis and treatment are extreme for rural people. Rural dwellers also tend to have a greater severity of other chronic health problems and a greater need for assistance with activities of daily living than do their urban counterparts. Furthermore, their families' purchasing power is less than that of urban families in Montana. While family and formal care is important, rural individuals depend more on informal voluntary care from community members than do urban people.

Cancer is most prevalent among older individuals who are especially affected by the availability of and access to health care. They also experience unique circumstances that complicate cancer care regardless of where they live. However, the actual assistance from family, informal, and formal sources was less for older individuals with cancer than for younger ones. This finding is true despite the greater severity of other chronic health problems in older people and their reported need for more assistance. Moreover, the caregivers of older individuals also reported greater severity of chronic health problems that may limit their capability to provide care to their loved ones. In this study, both caregivers and individuals with cancer scored higher than the general national population on an index of depression. Scores of ill persons were unrelated to their place of residence or age, but were higher for those who were seriously ill, had severe chronic health or financial problems, or perceived less overall social support. Family satisfaction was also unrelated to place of residence, but older individuals tended to be more satisfied family members than younger ones.

The study findings suggest several general recommendations to improve the cancer care system in Montana.

- Establish support groups
- Establish information centers
- Increase home-care and home-chore services
- Provide temporary accommodations for patients and their families while in treatment away from home
- Provide incentives to promote family and informal care through public policies
- Increase insurance coverage

Alternative cost-effective methods of delivering various types of services and assistance over wide geographic areas should be studied and applied to the above recommendations. Three alternative methods are common.

- Community-based services
- Family education and training
- Communications technologies

Most states are searching for solutions to health care for people living in rural regions. This analysis and the comments by Montana families living with cancer support the options recommended here ■

Montana Dept. of Commerce, G. Wunderwald

INTRODUCTION:
Families Living With Cancer

Family health care needs and the problems of providing cancer care are expected to be greatest in rural areas. Rural people are also expected to face the greatest barriers in accessing formal cancer care. In addition, options for expanding health care services are most limited in rural areas where health care resources are scarce. Health care professionals, policy makers, and planners may discover ways to improve and implement cancer care services by examining how rural families manage cancer and what these families indicate as needs.

Three out of four American families will deal with cancer and its treatment, its health care demands, and often the death of a loved one to the disease, according to the American Cancer Society (1,2).[1] Using census figures, this translates into approximately 154,000 Montana families who are likely to be touched by the disease. These families will need access to formal health care services. However, access for these families will be complicated by distance that must be traveled for services, harsh weather during travel, and limitations on the kinds of services that are available. In addition, much care for persons who have cancer will be provided through informal, voluntary care given by individuals outside of the household and through family care given by household members.[2]

Earlier detection and treatment have lengthened survival of individuals with cancer, while changes in health care financing have shortened the length of stay for cancer patients in hospitals and acute care facilities. Therefore, home care of individuals with cancer is becoming more demanding. Family members are included in administering complex treatments, medications, and procedures as well as in monitoring changes in health status and assisting with everyday activities of living. Consequently, family members and informal caregivers face tasks relating to cancer care about which they may have little information and for which they may have few skills.

Family health care needs and the problems of providing cancer care are expected to be greatest in rural areas. Rural people are also expected to face the greatest barriers in accessing formal cancer care. In addition, options for expanding health care services are most limited in rural areas where health care resources are scarce. Health care professionals, policy makers, and planners may discover ways to improve and implement cancer care services by examining how rural families manage cancer and what these families indicate as needs.

Health care problems, caregiving roles, and experiences of families living with cancer are also expected to depend upon the ages of individuals with cancer and their family members. Older individuals may have health problems in addition to cancer. Likewise, older family caregivers may have health problems that limit the assistance they can provide. Such problems and limitations must be accommodated in the cancer care system. Because the proportion of older people will increase to as much as one-fourth of the population as baby-boomers age during the next few decades (39), older families living with cancer will be an increasingly larger segment of those served by our health care services.

Few studies have described the role of families living in

[1]Numbers in parentheses refer to items in the literature cited references at the end of this report.

[2]The following terms are used throughout this report: family care—assistance to the ill person given by members of that household; informal care—assistance to the ill person given voluntarily by individuals outside the household (including relatives); formal care—paid assistance and services for the ill person provided by members of the health care system.

sparsely settled regions who care for their ill members and cope with cancer. One study of rural Montana families who manage cancer was conducted by the Montana Family Cancer Project in 1990.[3] Data from that project form the basis for this report.[4]

This report describes health care circumstances of individuals with cancer, including the availability and accessibility of health care; their health care needs; contributions of formal, informal, and family care; and the impact of the illness on family members who manage the illness at home. Special emphasis is given to the effects of age and rural location upon family experiences.[5] In addition, this report explores potential changes in Montana's health care systems that could better serve the older population as well as people in rural areas. The following sections describe the experiences of individuals with cancer and their family caregivers.

- Cancer in Montana: The Study Families
- Barriers to Cancer Care: Availability and Accessibility of Health Care Services
- Barriers to Cancer Care: Health and Employment of Caregivers and Family Finances
- Cancer Care: Needs of Individuals with Cancer
- Cancer Care: Assistance Provided
- Effects of Living with Cancer: Family Life

In addition, this report aims to contribute to improving health care services for rural families and to helping individuals with cancer and their families manage the illness. The final section of the report includes recommendations for improving cancer care for the families described in this publication.

Planning for support from within the family may be even more important in Montana than elsewhere because of distances, harsh weather, and limited health care services. Consequently, health care providers must recognize the role of families. In addition, they should design services to help families manage illnesses at reduced costs while maintaining a quality lifestyle ■

Montana Dept. of Commerce, D. O'Looney

[3]"Home Health Care of Rural Cancer Patients in Montana" funded by the National Institutes of Health, National Cancer Institute (1R01CA46330). Co-principal investigators were Clarann Weinert, S.C., Ph.D, R.N. and Lloyd D. Bender, Ph.D.

[4]"Families Caring for Older Rural People with Cancer" funded by the AARP Andrus Foundation. Co-principal investigators were Clarann Weinert, S.C., Ph.D., R.N. and Lloyd D. Bender, Ph.D.

[5]For ease of presentation in this report, place of residence is classified as urban, rural, or isolated rural on the basis of accessibility to health care services. A technical formula assigned rankings with higher scores indicating more urban and lower scores indicating more isolated rural residences. The ranking was based on county populations and distance from the residence to emergency medical care.

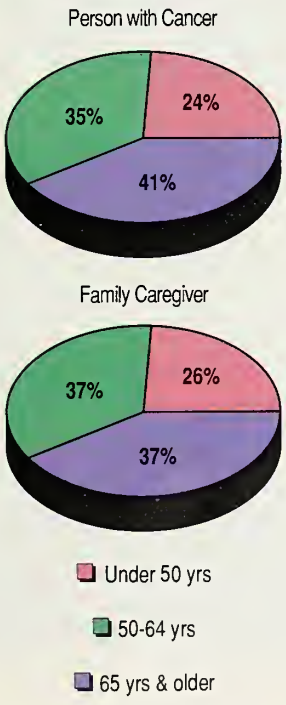
American Cancer Society

The geographic area represented by the data in this study included 47 of the 56 counties in Montana and six bordering Wyoming counties which use Montana's health care services. The 422 families from this wide area reside in a variety of locations. About one-third lived in or near cities. The rest lived in small towns, in rural areas surrounding towns, or in more isolated areas.

The data were collected from these families as part of the Montana Family Cancer Project at Montana State University College of Nursing. The families who voluntarily contributed data joined the project between August 1989 and September 1990.[6] As families joined, they were initially interviewed by telephone. Subsequently, individuals with cancer and their caregivers completed questionnaires.

The demographic data about individuals with cancer and their caregivers described respondents' racial/ethnic group, age, educational background, composition of family household, and the relationship of the caregiver to the family member with cancer. All but one of the respondents were white, which closely reflects the racial/ethnic population of Montana. According to the 1990 census, 93 percent of the population were white; six percent were American Indian; and 0.3 percent were black (39).[7]

Figure 1
Age of Respondents

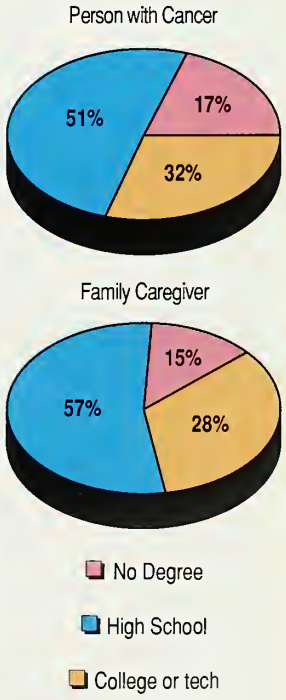


Individuals with cancer and their caregivers were categorized into three groups by age: a) below age 50; b) age 50-64; c) age 65 or older. For individuals with cancer, 24 percent were below age 50; 35 percent were age 50-64; and 41 percent were age 65 or older. The ages of the caregivers were similar to the ages of the individuals with cancer (see Figure 1).

The educational background of the respondents was varied. Of the individuals with cancer, 17 percent had not graduated from high school; 51 percent had no more than a high school education; and 32 percent had college or technical training. Caregivers had slightly lower educational levels than individuals with cancer (see Figure 2).

The households of the study families were primarily composed of two people (70 percent).[8] The remaining 30 percent were families with children or other adults in the home. The family member providing assistance in managing cancer was primarily the spouse (91 percent). Others living in the household and identified as caregivers were children (5 percent), parents (2 percent), siblings and friends (2 percent).

Figure 2
Education of Respondents



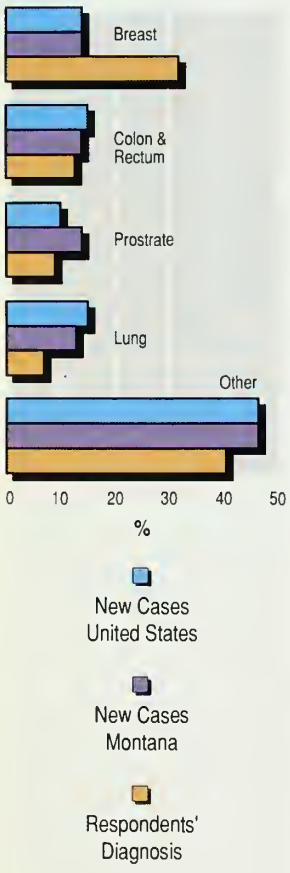
[6]Since families joined voluntarily, generalizations cannot be made to the entire Montana population.

[7]Minority populations are worthy of special study using survey instruments that have been developed for their unique cultures.

[8]The term 'family' in this report refers to those individuals living in the same household. Individuals living alone were not included in these data.

CANCER IN MONTANA:
The Study Families

Figure 3
Cancer Sites: United States, Montana and Study Respondents 1990

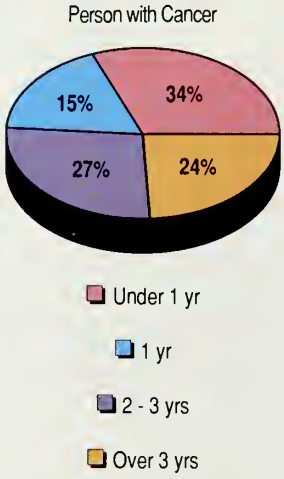


The patterns of cancer in the state are similar to those of the nation, as indicated by the diagnoses of new cancer cases in Montana and the United States in 1990 (see Figure 3). The largest proportion are breast, colon and rectum, prostate, and lung. The distribution of cancer types for those who volunteered for the Montana Family Cancer Project was slightly different from the newly diagnosed cancers in Montana and the United States. In particular, breast cancer was over-represented, while the numbers of colon, prostate, and lung cancers were somewhat under-represented. However, the types of cancer reported by individuals living in Montana cities were the same as for individuals living in more rural areas.

While cancer may strike at any age, most diagnoses are made after mid-life. According to the Montana Central Tumor Registry data for 1979-1988, 84 percent of cancer diagnoses were made at age 50 or later (23,24). However, cancers found in men were typically diagnosed late in life. Before age 50, only 10 percent of all cases in men had been diagnosed. For women, 23 percent had been diagnosed before age 50 (24). Taking all ages into account, the numbers of men and women in the Montana Central Tumor Registry are nearly the same (24).

In the study sample, the numbers of men (193) and women (229) with cancer were similar. Seventy-six percent of the individuals with cancer were age 50 and over. However, the average age of women with cancer was lower (56 years) compared to men (63 years), resulting in a predominance of women in the younger and men in the older age groups.

Figure 4
Years Since Diagnosis



The 422 families in this study represent a cross-section of the Montana population. They live in diverse areas of the state; they have different educational backgrounds; and they include various age groups. However, these families have one unifying characteristic. Each household includes an individual who has been diagnosed with cancer. For 24 percent of these families, the time since diagnosis has been more than three years; 27 percent have been diagnosed for two to three years; 15 percent have been diagnosed for one year, and 34 percent have been diagnosed for less than one year (see Figure 4). Although these families have been living with cancer for varying lengths of time, they have a commonality of experience: coping with the care of ill family members and accessing the health care system for diagnosis and treatment ■

American Cancer Society

BARRIERS TO CANCER CARE:
Availability & Accessibility of Health Care Services

Many Americans take for granted their access to a health-care system...Economic factors...are the most significant barriers to access. But a long, troubling list of additional barriers—age, race, geography, marital status, transportation and language, to name just a few—also loom as major obstacles for those seeking care. Modern Maturity, (12)

Montana Dept. of Commerce, J. Wylder

Barriers to availability and accessibility of formal cancer care services in Montana may mean that families living with cancer are placed under additional physical and emotional stress. Several features of Montana contribute to these barriers. The vast land area of the state and the very low density of population result in a limited number of locations for health care services. In addition, the harshness of the long winter season is a problem for families who must travel to distant care facilities. Therefore, questions relevant to availability and accessibility of health care services in Montana should be examined.

- What characteristics of Montana limit the availability of health care services?
- What distances are traveled for health care in Montana?

Availability of Services

Montana is the fourth largest state, with a total population of about 800,000 and a population density ranking 48th in the nation. Only ten of the 56 counties in Montana have more that six people per square mile. The average population density of the state is only 5.5 people per square mile. Only two counties within the state have cities with enough population (more than 50,000) to be classified as metropolitan statistical areas by the U.S. Bureau of the Census (see Figure 5). Consequently, many Montana counties are so sparsely populated that health care services are limited.

Because population density is so low and the land area is so large, the state can support only a few specialized cancer services. Thus, the major medical centers in Montana serve very large regions. For example, Montana has only five radiation oncology treatment centers, located in Billings, Great Falls, Missoula, Kalispell and Butte (see Figure 5). In addition, surgery, chemotherapy, and other support services are available in the 65 hospitals throughout the state. However, services are limited in the smaller communities and in regions with low population densities. One family member, living in an isolated rural area, summarized this problem: "We attempted to care for our son at home for the last [weeks] of his life. He was extremely disabled and needed constant nursing care. Rural Montana provides almost no organized care for such a situation.... Something needs to be done to help rural Montanans when they need to care for cancer patients in the home!"

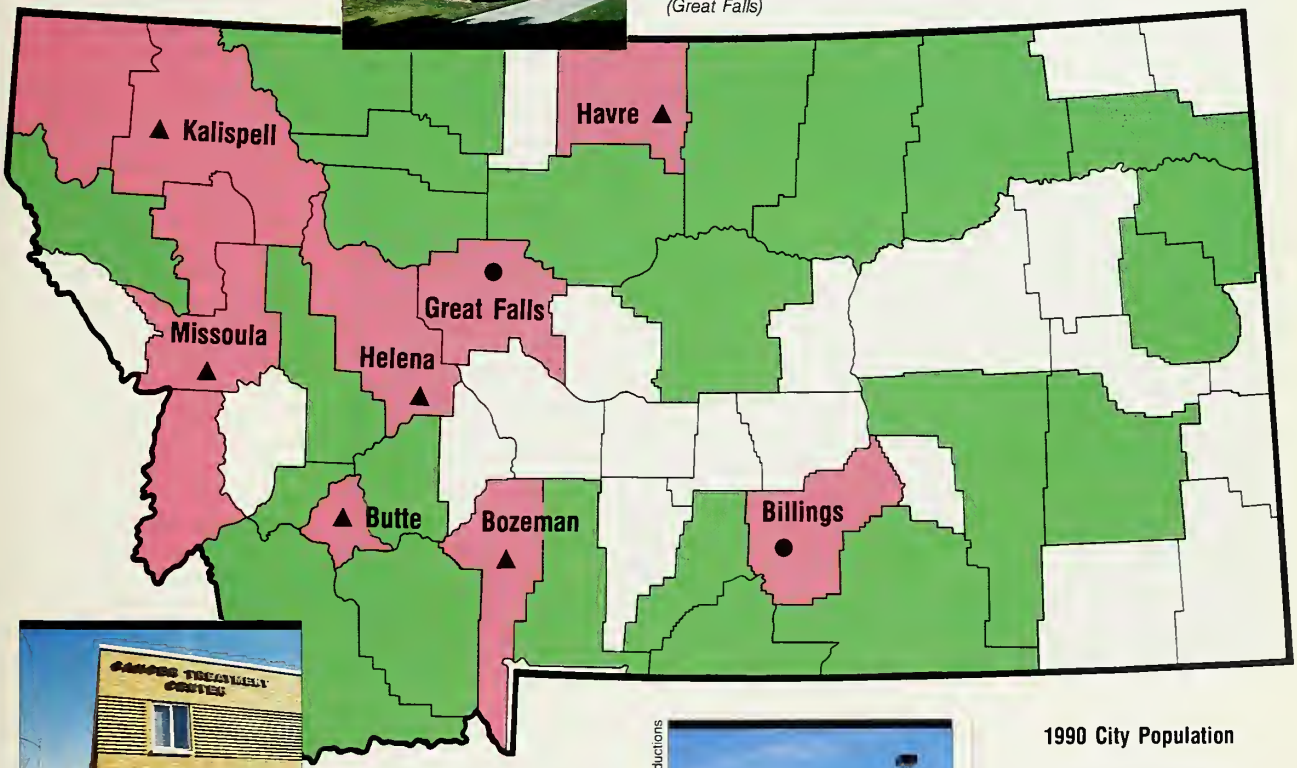
Kalispell Regional Hospital Cancer Center (Kalispell)

St. Patrick Hospital Cancer Center (Missoula)

Columbus Hospital Gift of Life Regional Cancer Center (Great Falls)

Figure 5

Montana County & City Populations and Cancer Treatment Center Locations



St. James Community Hospital Regional Cancer Treatment Center (Butte)

High Plains Productions

Northern Rockies Cancer Center (Billings)

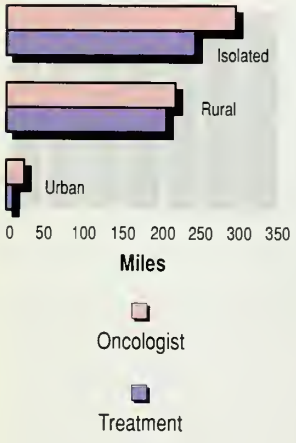
1990 City Population

- ● Greater than 50,000
- ▲ 10,000 to 50,000

1990 County Population

- Less than 5,000
- 5,000 to 15,000
- Over 15,000

Figure 6
Average Miles to Cancer Services
(Round Trip)



Accessibility to Services

The distance to specialized cancer care services in Montana is a major barrier for families living with cancer. People in or near urban areas generally have access to such specialized services. However, people in more isolated areas have few local services available; consequently, they must spend more time traveling to larger urban areas where specialized cancer care services are available. For these people, travel may be a major problem. It is expensive; it requires time away from work and home; and it places additional stress upon the family.

Distances traveled to cancer care services by the study families depended on their location in Montana. Their places of residence represented a broad mix of locations throughout the state. Fifty-two percent of the families listed a rural residence located in hometowns smaller than 5,000 population or in the open country on farms and ranches. An additional 15 percent of the study families lived in towns with populations between 5,000 and 15,000. The remaining families (33 percent) lived in cities with populations ranging from 15,000 to 81,150—Montana's largest city. Consequently, for the majority of these families, cancer diagnoses and treatments involved extensive travel. The spouse of an individual with cancer commented, "...[on] the difficulty that transportation can be for rural Montanans. Doctors are few and far between [here]. It is a matter of special care in a few centers in the state. We had to travel 220 miles every time that we had an appointment. As the weather got worse, crossing the [Continental] Divide became more difficult."

For families living in isolated areas, a round trip to the specialized care of an oncologist averaged 296 miles; for families in other, less isolated rural locations, the average mileage was 214 (see Figure 6). In contrast, the round trip to an oncologist for families living in urban areas was only 24 miles. In addition to this in-state travel, it is not uncommon for Montana families to travel to Seattle, Salt Lake City, Denver, Minneapolis, or other major medical centers for diagnosis, particular types of treatment, and long-term follow-up.

At the time of the interviews, 47 percent of the individuals with cancer were receiving treatments, with 116 receiving treatments weekly or more often. Because some treatments such as chemotherapy may be administered at nearby health facilities, the distance traveled by the study participants for treatment was shorter than the distance to oncologists. Still, treatment travel averaged 140 miles round trip, with families in rural and isolated areas traveling more than 200 miles round trip.

Travel to treatment and care not only produces stress, it also requires time and money. The costs of travel limit family resources which are necessary to provide other kinds of care. However, the financial burden includes more than the obvious car expenses. One young caregiver emphasized the costs that travel incurred: "Traveling...costs [include] babysitting, loss of pay, [boarding] pet at vet, food, lodging, phone. All of these add up quickly, and there is no reimbursement. They strain finances as much as the health care cost."

The availability and accessibility of health care services in Montana clearly are limited, especially in rural regions of the state. Moreover, gaining access to cancer care involves much more than medical and travel expenses, as indicated by the respondents. While such direct costs limit access to health care, the personal circumstances of the family may also limit care ■

Montana Dept of Commerce, D. O'Looney

Personal circumstances such as poor health and financial problems limit the care families can provide.

Even with a will to create a supportive and caring environment, family caregivers face barriers, including personal and family limitations, that prevent them from giving the quality of care they may wish to give. Personal limitations include problems with the health of family caregivers and the employment of caregivers. A second type of barrier is the family's financial status. Inadequate family finances may limit the type of care and the quality of care that can be obtained. Thus, barriers regarding the health and employment of caregivers and the financial status of families need to be assessed.

- Which caregivers have health problems?
- Which caregivers are employed?
- What families have concerns about personal finances?

Montana Dept. of Commerce, D. O'Looney

Health Problems of Caregivers

Family caregivers who have chronic health problems such as heart disease, arthritis, obesity, and poor eyesight may be limited in the activities and assistance that they can provide for family members with cancer. Although chronic health problems may affect caregivers of all ages, the data from this study confirm that chronic health problems are more likely among older family members. Family caregivers age 65 and older reported the greatest number of limiting health problems. In addition, caregivers in isolated rural regions reported considerably more health concerns than did caregivers in urban areas. Older, rural caregivers may be most limited by their health in providing care. One 75-year-old woman commented about caring for her husband: "I am constantly wondering about when or where the cancer will become active again, and will I be able to care for my spouse, or even be here when that time comes. My own health has a lot to do with my [concerns]. I have conditions that are not going to get better...."

Employment of Caregivers

When caregivers are employed, family problems multiply. The time to assist ill family members is limited if the caregivers are employed outside of the home. According to one national study (11), three-fourths of the men and over half of the women who provide care for ill family members were employed. A second national study found that 55 percent of the individuals who provided home care for ill family members age 50 and over were employed (30). In addition, a third national study revealed that three-fourths of the caregivers believed that caregiving interfered with their work life (5).

The employment status of family caregivers in this study parallels national studies. Approximately one-half of the family members who were assisting with home care were employed outside of the home. Few caregivers who were age 65 or older were employed. However, of the family caregivers under age 50, 98 percent of the men and 88 percent of the women were employed outside of the home. These younger caregivers who are employed may have less time to help ill family members and use more outside care assistance than older caregivers.

The strains that are a result of the employment of caregivers are suggested by one case: "My husband's occupation as a truck driver has made our situation more challenging at times. If he is home 24 hours a week, we are lucky.... I have been forced to be independent despite my cancer. Maybe that has been good. We have three children still at home."

This study also revealed that some caregivers have conflicts between their employment and the care of ill family members. In fact, providing care for the very ill may be as time-consuming as a full-time job. Previous national studies have suggested that "role overload" may produce what is commonly called "burnout" of some caregivers (7). A respondent mentioned the problem of taking time from work to travel with his ill spouse for treatments: "Travel has to be done around my work schedule. It would have been best for the treatments to take place on Saturday, but no treatment was available on the weekend, and no exceptions could be made even though we were driving [over 500] miles." Finally, when time demands became too great, five of the caregivers from this study found it necessary to quit their jobs.

Family Finances

The ability to support the costs of cancer care depends upon family financial resources. Family incomes are important, but other resources also support cancer care. Diminished employability of the person with cancer affects future income as well. Lack of insurance or poor coverage may mean that families must exhaust their savings in paying for care. Thus, families living with cancer have ample reasons for concern about their financial status.

Numerous national studies have documented the low incomes of families living in isolated rural settings (15,27,37). In this study incomes of families living in isolated rural areas, regardless of age, averaged lower than the incomes of families living in less isolated locations. The difference in income was greatest between families in urban areas and families in the most isolated rural areas, where 45 percent of all families had household incomes under $17,000.

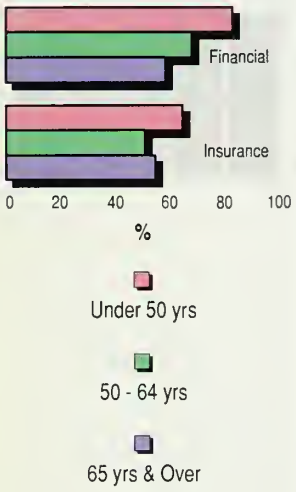
Low incomes of older people have also been documented nationally (16). In this study, the average family income for older individuals with cancer was lower than the family income for younger individuals. Of the families of ill members over age 65, 44 percent had household incomes under $17,000, compared to 38 percent of those age 50 through 64, and 22 percent of those under age 50. These incomes may be contrasted to $21,500, the estimated Montana median family income in 1988, adjusted for two-person families.

... Caregiving can be the equivalent of taking on a second job for those who work outside the home.

Modern Maturity, (12)

BARRIERS TO CANCER CARE:
Health & Employment of Caregivers & Family Finances

Figure 7
Financial & Insurance Concerns
Person with Cancer



The study found that families with members over age 65 and living in isolated rural areas had the lowest average income ($15,500). For these low-income families, obtaining medical and other health care services may present financial problems. One older individual expressed concerns about the cost of medication: "Why are...pills so expensive? This is our only problem. Seventy dollars [for] sixty pills is hard on a small social security check."

The loss of income due to the lack of employability of a family member with cancer contributes to family financial problems. In this study 56 of the individuals with cancer (13 percent) said they were unemployed due to their illness. Therefore, when families lose earning power because of cancer, financial stress increases. One respondent commented about his financial concerns: "[I experienced] job discrimination. Since having to retire [at age 38], I have been unable to find gainful employment to adequately support my family's needs. There is also discrimination in securing financial loans, mortgages, and insurance." A caregiver commented, "My husband has had a lot of difficulty finding employment after being forced to retire.... There has been a lot of stress caused by financial problems—I strongly feel his health record is the reason for trouble finding work. I have had problems with taking time off work to be with my husband for...exams, operations, etc."

Although a majority of individuals with cancer expressed financial concerns, and families with older members tended to have the lowest incomes, younger individuals in the study expressed greater concerns regarding financial problems. Eighty-three percent of respondents under age 50 had financial concerns, such as inadequate funds to pay for medical expenses and basic living expenses (see Figure 7). In comparison, 59 percent of those over age 65 expressed similar concerns.

In this study, insurance concerns were also greatest among the younger family members with cancer, despite the fact that most were insured. Sixty-five percent of the individuals under age 50 felt insurance concerns, compared to 55 percent of those age 65 and over. Forty percent of the individuals with cancer were covered by Medicare, often in combination with supplemental insurance, and almost one-half were covered by private insurance alone. Only 11 individuals in the study were not covered by some type of insurance, and only 23 were in the Medicaid program. The fact that older individuals with cancer in the study tended to have less concern about insurance coverage than younger ones may reflect differences in coverage of Medicare and its supplements compared to private insurance coverage held by many young people.

Personal circumstances such as poor health and financial problems do limit the care families can provide. Regardless of the family's capacity to provide care, cancer demands more and different types of care than many other illnesses. In addition to complex treatments and everyday health care, living with cancer creates unique needs and concerns ■

Montana Dept. of Commerce, G. Wunderwald

CANCER CARE:
Needs of Individuals With Cancer

Because of the fearful nature of the disease, individuals with cancer, regardless of their physical condition, have special needs for encouragement and information (17, 31, 42)

American Cancer Society

American Cancer Society, Werner Wolff

The intensity of cancer care needed by an individual may fluctuate throughout the course of the illness. Some individuals may require a great deal of assistance for a brief period during and after treatment, with little help needed beyond that. Other individuals may require a high level of care for long periods after treatment. Still others may require little care initially, with more care needed as cancer progresses. Study interviews indicated only the experiences and needs felt at the time of the interview.

However, experiences and needs over the full range of care levels have been documented because of the large number of respondents in this study.

Daily care needs of individuals with cancer were explored through the five questions below.

- What care levels are required?
- Does the ill person have health problems in addition to cancer?
- Where did the ill person get assistance?
- Does the ill person need assistance for daily living?
- What special needs does the ill person have?

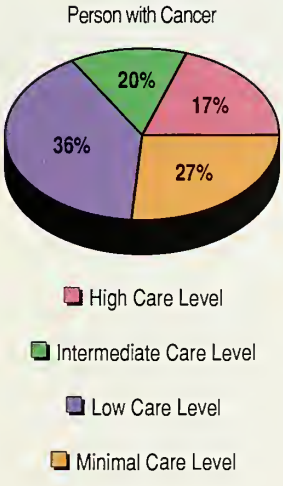
Care Levels

Four levels of physical care required by individuals with cancer were assigned at the time of the first telephone interview. The care levels ranged from high to minimal levels. The highest level of care required someone else to assist the ill person with treatments and complex procedures or to provide ongoing supervision. Only 17 percent of the respondents were in this group (see Figure 8). The next highest care level, the intermediate care level, required direct physical care which included assistance with intermittent problems of nausea, routine medications and injections, or normal activities of daily living. About 20 percent of the respondents were at this level. The third level (36 percent of the sample) had low care requirements, such as transportation or assistance with special diets. The fourth level (27 percent) included individuals with cancer who, at the time of the interview, were fully independent, requiring almost no direct assistance.[9] It should be recognized that stress occurs at all care levels, and support for social and emotional needs continues to be important. Comments such as "...It takes months to learn to live with the fear and finally push it into the back of your mind...." were common. The wide range of care levels is important to consider when findings from the data are discussed.

Other Health Problems

The severity of other chronic health problems, such as heart disease, complicates a family's ability to manage the cancer. Nearly half of the individuals with cancer reported three or more complications which resulted from other health problems. One caregiver stated, "...cancer is the second major disease suffered by my husband. We already were in stress [when cancer appeared]."

Figure 8
Care Level



The overall severity of chronic health problems in this study is indicated by both the number of health problems and the severity of each individual problem.[10] This measure of the severity of chronic health problems was used in making comparisons between younger and older people, and between rural and urban residents. Chronic health problems are expected to be more severe among older than younger people and among rural residents in relation to urban residents, regardless of age (28,41).

As expected, the data indicated that chronic health problems were associated with both age of the ill person and place of residence. Older individuals with cancer tended to report greater severity of chronic health problems than did younger ones. In addition, individuals with cancer who lived in the most isolated places, regardless of age, tended to report more severe chronic health problems than those who lived in less rural places. Finally, when both age and residence were considered, the chronic health problems of individuals with cancer were most severe for older persons living in isolated locations. Therefore, it would seem likely that the challenge of providing care would be greatest for these individuals.

Cancer Care Levels

Support for social and emotional needs is understood to be an important element for all care levels.

High Care Level

Person with cancer requires someone else to assist with treatments, technical procedures, on-going physical or mental supervision, or a patient who is bed-ridden 15 or more hours per day.

Intermediate Care Level

Person with cancer requires someone else to assist with intermittent problems such as post-treatment nausea; routines in which the cancer patient is partially independent such as oral medications or shots; normal activities of daily living such as eating, walking or standing; or treatments that are not complex.

Low Care Level

Person with cancer requires someone else to assist with cooking to meet the needs of a special diet, transportation, yard or housework that the cancer patient formerly did independently.

Minimal Care Level

Person with cancer is fully independent and requires no outside assistance or alteration in the household environment.

[9]Level of care was taken into account in all of the statistical findings described in this report. As a consequence, statistically significant variables were significant regardless of the level of care. For example, chronic health problems were found to be more severe in older individuals whether their care level was high or minimal.

[10]The correlation between the score for health problems and the level of care is only 0.14, indicating that the variables measure two different health conditions.

Sources of Assistance

Individuals with cancer were asked about the assistance they received—from family members, informal networks, and formal care providers—because it was expected that the number of assistance sources would be different for older individuals and for people living in isolated rural areas. Assistance covered in this study included needs related to transportation, finances, insurance, medical information, home care information, and spiritual and emotional concerns.

American Cancer Society

The assistance provided by both family and informal networks was related to the age of the ill person. When the relative seriousness of each individual's cancer was taken into account, older individuals received assistance from significantly fewer sources within their families and informal networks than did younger people. In addition, older individuals with cancer reported receiving help from slightly fewer formal health care sources than did younger people. The data do not reveal the reason for the low numbers of assistance sources for older people in relation to younger people, but those reasons are worthy of additional study.

Previous studies have shown that rural communities have fostered more caregiving from informal sources than have urban communities (13,40). In this study, individuals living in rural areas received assistance from significantly more informal sources outside the home than did urban residents, regardless of age. Thus, friends, neighbors and nearby relatives in rural communities are important sources of help for families living with cancer.

Assistance Needed for Daily Living

Each ill person was asked questions relating to the assistance that was needed in certain daily activities. These activities include eating, dressing, walking, traveling, bathing, and toileting.

Only 14 percent of ill respondents needed assistance from another person for any of the above activities. The expressed need for assistance was related to place of residence, care level, and age of the ill person. As expected, those who were most ill, people living in rural areas, and older individuals were the most likely to need assistance with activities of daily living. Twenty percent of those 65 and older needed such assistance, compared to 10 percent for the remainder of the respondents. The greater need of older people in relation to the lower assistance they received is a discrepancy that has been noted elsewhere in the professional literature (20, 29).

American Cancer Society

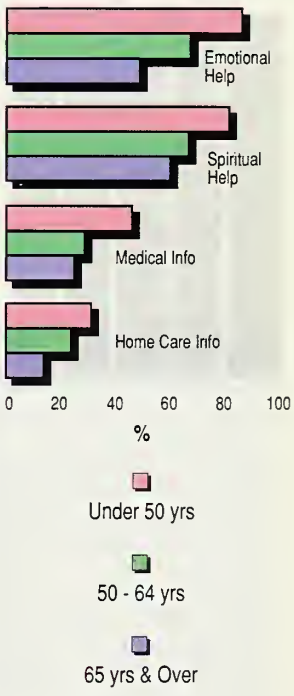
Special Needs of Those With Cancer

Because of the fearful nature of the disease, individuals with cancer, regardless of their physical condition, have special needs for encouragement and information (17, 31, 42). These special needs include emotional and spiritual help, and medical and home care information. In contrast to the low proportion of respondents needing assistance with activities of daily living, 84 percent felt one or more of these special needs. Emotional and spiritual needs were expressed most frequently. Medical and home care information were also considered more important needs than help with activities of daily living.

A higher proportion of individuals under age 50 felt a need for help and information compared to older respondents (see Figure 9). Although those age 65 and over were less likely to express needs for help and information, large proportions of these older individuals felt the need for emotional (49 percent) and spiritual (60 percent) help.

These special needs of individuals with cancer intensify all their other needs for support and care. The resulting stresses complicate the jobs of family, informal and formal caregivers. In particular, the viewpoints of family members can add important information for understanding the effects of living with cancer ■

Figure 9
Expressed Needs
Person with Cancer



Caregiving is typically performed by relatives and close friends and generally involves activities related to managing a household as well as activities related to direct care of the individual such as bathing, feeding, dressing and toileting.

... the burden of caregiving can create physical, economic and emotional stresses for caregivers...

American Association of Retired Persons, (30)

American Cancer Society

Providing assistance to a person ill with cancer is a challenge in numerous ways. While much of the assistance is provided by family members, meeting caregiving challenges may become a joint activity where family and other care providers work together (14). One family indicated the value of this working relationship: "...It was only through our acquaintance with a very giving nurse who lives in the area that we were able to [manage] at all. We called her for advice at all hours of the day and night..."

The support available to meet the needs of individuals living with cancer was documented in three ways from the perspective of the caregiver.

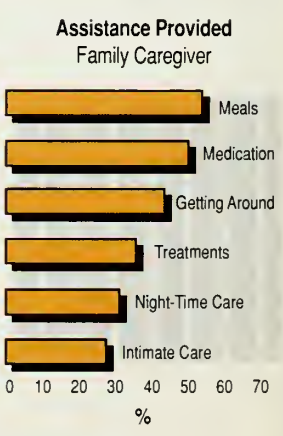
- What assistance did the caregiver provide?
- How much overall social support did the caregiver perceive?
- Was the management and treatment of the disease by health care professionals satisfactory?

Assistance Caregivers Provided

Family caregivers gave many types of help in performing various daily activities for their ill members. Overall, 72 percent of the family caregivers reported performing one or more common activities as a part of their responsibility. Fifty-three percent of the caregivers indicated that they prepared meals for ill family members (see Figure 10). Help in administering and monitoring medications was a task that 50 percent performed. Family caregivers also frequently provided assistance in traveling and getting around in the home (44 percent) and assistance with treatments (37 percent). Finally, family caregivers also provided care during the night (31 percent) and intimate care (27 percent).

Caregiving activities were related to the age, and may be related to the health of the caregiver. In general, a much larger proportion of young caregivers reported providing more and different kinds of home assistance than did older caregivers. Most younger caregivers also reported few chronic health problems of their own; thus, they may have been physically able to provide more care. These facts may be related to the previous finding that older individuals with cancer received less family care than did younger ones.

Figure 10



Deacones Medical Center

Stress in caregivers may be generated by the constant day-to-day responsibilities and concerns for the ill person as well as by the performance of everyday tasks. The professional literature refers to such responsibilities and concerns as the "invisible" work of caregiving that is difficult to measure although it results in a burden for caregivers (4). In this study 70 percent of the caregivers reported feeling responsibility and concern for ill family members. Taking responsibility for the well-being of the ill person was reported by 59 percent of the caregivers (see Figure 11). In addition, 46 percent of the caregivers listed being available at all times as one of their experiences. The uncertainty of being able to provide care in the future and the inability to do anything about the progress of the disease were other major concerns of caregivers. Such feelings of concern and responsibility, especially if experienced over long periods of time, add to the burdens and stresses of caregiving.

Overall Social Support

Overall social support perceived by caregivers is a key to reducing stress. Just knowing that someone is waiting and willing to perform tasks that become too burdensome can be a comfort to caregivers (20). Other studies have concluded that the certainty of having such assistance and support at hand from family and informal sources is the single most important support that others can give to individuals with cancer and their families (25).

In this study, the overall social support that caregivers perceived to be available was related to the seriousness of the illness and was not directly related to the ages of the caregivers or their places of residence. When high care levels were required by individuals with cancer, caregivers felt there was less overall social support available. In contrast, when family members with cancer were not seriously ill, caregivers perceived overall social support to be available. An interesting finding is that women caregivers generally felt more overall social support was available than men caregivers did.

Satisfaction with Health Care Professionals

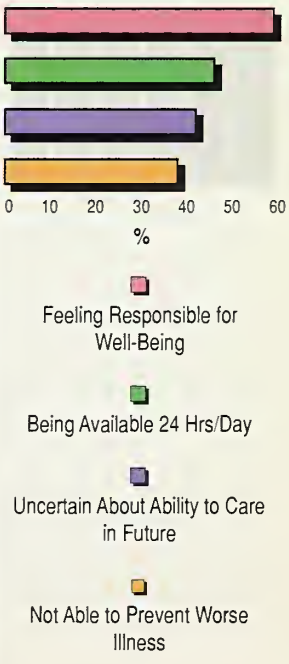
Health care professionals provide part of the support to individuals with cancer. Caregivers were asked questions that related to their satisfaction with the management and treatment of the cancer illness by health care professionals. Satisfaction with health care professionals was generally reported as high. However, older people expressed greater satisfaction with the way health care professionals managed and treated their ill family members than did younger people. The satisfaction of caregivers with health care services of professionals was not related to either the seriousness of the illness or to the location (urban or rural) of the household.

Regardless of satisfaction with health care professionals, care providers in the household, as well as the ill person, face responsibilities and concerns that are difficult. Support from informal sources lessens the burden of providing care day-in and day-out. However, even if support may be available, living with cancer generates emotional strains on both the ill person and family members, affecting them and their family life ■

"...It was only through our acquaintance with a very giving nurse who lives in the area that we were able to [manage] at all. We called her for advice at all hours of the day and night...."

Figure 11

Feelings of Responsibility and Concern
Family Caregiver



EFFECTS OF LIVING WITH CANCER:
Family Life

Cancer may also produce stress by placing emotional and physical demands on family members.

Cancer is an illness with serious emotional and psychological strains that can produce depression and dissatisfaction with family life for both the ill person and the caregiver. The shock of the diagnosis, followed by the mechanics of getting medical care and managing the illness, especially over long periods of time, can be very stressful. Single-handedly providing everyday assistance to the individual with cancer and maintaining a home, in addition to assisting with the management of the disease and its treatment, can be burdensome for a family caregiver. If the illness is life-threatening, fear of the future and the loss of control over family affairs can be very strong. Negative reactions of friends add to the stress. As a caregiver stated, "A difficult emotional aspect for cancer patients is how their friends react towards them. In our case, my husband's friends were very scarce, almost as if it was contagious.... It's hard...for the person with cancer to be going through the disease, plus feeling abandonment by friends who are 'uncomfortable'."

Dealing with depression can be a part of living with cancer and should be a surprise to no one. One person with cancer expressed her feelings: "Cancer is, for rural people, a very lonely experience, and as prevalent as the disease is, not many people can understand the emotional toll it takes on the patient."

Even though the psychological and emotional effects of living with cancer may be hard to measure objectively, some of the questions asked in this study were designed to assess how well individuals were coping and how well couples and families felt they were getting along and working together. The responses to these questions describe living with cancer from the perspectives of both the ill person and the family caregiver.

- Are the ill person and the caregiver depressed?
- Are family relationships satisfactory?
- What coping strategies are people using?

American Cancer Society

Depression Among Individuals with Cancer and Their Caregivers

In each family, both the person with cancer and the caregiver answered a set of questions that measured level of the psychological depression (32). Participants' depression scores were compared to national scores to estimate the number of individuals in the study who may be at risk for clinical depression.

The responses of individuals with cancer in this study indicated an elevated risk for clinical depression. Thirty-one percent of the scores of these individuals were at or above levels high enough to classify them as at risk for depression. In contrast, only 17 percent of a national sample of the general population scored as high. When individuals with the most serious and active illnesses were considered, 42 percent scored high enough to be considered depressed.

After adjusting for the seriousness of the illness, three additional factors were significantly associated with the depression scores of individuals with cancer: chronic health problems, perceived financial problems, and overall social support. More severe chronic health problems and greater concerns about perceived financial problems were associated with higher depression levels. Low perceptions of overall social support in this study were also associated with higher depression levels. The lack of support was graphically described by one individual with cancer: "I was fairly isolated as we live on a farm .... When my husband would go [to town], I'd stay out here alone .... Self pity and terror would overtake me for hours. I didn't want my friends to think I was weak, so I kept it all to myself. The result was depression."

Caregivers were also prone to more depression than the general population. As one caregiver stated, "Living with cancer is an emotional see-saw. When my husband is doing O.K., I'm O.K. When he's not, I'm a wreck." While fewer caregivers were seriously depressed compared to individuals with cancer, 25 percent of the caregivers' scores were still high enough to place them at risk for clinical depression. In addition, the average depression scores of caregivers were significantly higher than those of the national study.

The factors associated with caregiver depression were similar to those associated with depression among individuals with cancer. High care levels required by the person with cancer were associated with high levels of depression among family caregivers—36 percent of their caregivers scored high enough to be considered depressed. In addition, if caregivers perceived little overall social support, depression levels were high. Poor health of caregivers and their concerns over financial problems were also closely associated with high levels of caregiver depression. One caregiver's major concern, among others, was finances: "I worry that...we won't have the [financial] resources to get the best care we can get...it seems that we don't enjoy life as much because...concern about money and cancer has taken some of the joy out of life."

Two additional factors, associated with depression among caregivers but not among ill individuals, were the gender and ages of the caregivers. Depression scores were higher for women caregivers than for men. Other studies also reported that women typically exhibit higher depression scores (32). Furthermore, women caregivers in this study scored significantly higher than women in the general population nationally. In addition, depression scores tended to be higher for the younger caregivers than for the older ones. The fact that younger caregivers indicated higher levels of depression than older ones may be related to any number of concerns. A young woman, who cared for her husband, shared her concern about the future of her family: "Most couples our age don't think about time as being a factor. [They] assume they'll live to see their children grow, get married and have children of their own."

Family Relationships

Cancer may affect family relationships by disrupting lifestyles. Cancer may also produce stress by placing emotional and physical demands on family members. Some of these stresses on family relationships were described clearly by family caregivers. A caregiver stated, "It's hard for me even though I know he's probably not feeling well, and that's why he may be irritable." Another commented, "The children may get on his nerves easier because of his bad days."

Satisfaction with family relationships was documented in this study by a set of questions which summarized how the family unit functioned. In each family, the individual with cancer and the caregiver gave information separately. Based on these responses, three factors were found to be associated with the level of satisfaction in family relationships: level of depression, age, and overall social support.

The feelings about family satisfaction were similar for both the ill individuals and the caregivers. If depressed, each partner felt less pleased about the functioning of the family. Satisfaction with family relationships was higher for older people than for younger people, and individuals who had strong perceptions of overall social support had more positive attitudes about their family relationships. The positive effects that overall social support had upon family relationships was expressed by two individuals with cancer: "I am especially blessed by having a wonderful family who are able and willing to help me." ... "I try to face each day with a good attitude, and I do realize that everyone has given me the best of care and love." Another caregiver indicated the support given to her family by the community in which they lived: "Friends, co-workers, relatives had a benefit dance and auction for us to help with gas and motel...."

American Cancer Society

Coping Strategies

Although objective data were not collected to reveal the strategies of individuals and families, comments from study participants illustrated some of the ways they coped. Spiritual support was often described as a mainstay. Two respondents commented, "Cancer sets your priorities straight. I have a new lease on life. Every moment is precious. God has given me the power and purpose to do anything." ... "Personally, my strength has come from God and from my husband."

Other participants indicated that living each day at a time, keeping occupied, and having the companionship of pets were important elements in coping with their cancers. One individual in her seventies who had cancer stated, "I'm still active in my everyday life, go on vacations with my husband...love to sew and enjoy baking. I live a fairly normal life and enjoy playing pinochle with my friends." Another respondent commented, "I have a dog and a kitten.... They give me a lot of pleasure on good, bad, and painful days and do make me feel better."

Another important coping factor was the establishment of positive attitudes. One mother, who recovered from her bout with cancer, described her family and how they coped: "[Cancer] takes a toll on young children.... As a single parent and [with] children [10 and under]—the pressure and fear they experience, the changes it created in their lives...the fear of my leaving for a day or two...the fear of reoccurrence...the protectiveness, and on the other side, the pride they have for my strength and survival...their ability to trust...their true respect for life...for everyone.... This created children more mature than their peers, strong, independent, hopeful, loving and helpful. Patience and honesty are the two best gifts to share throughout cancer."

The emotional toll of living with cancer is reflected in the feelings of both the ill persons and caregivers. Overall social support along with adequate financial resources and insurance coverage lessen that toll. Some are able to cope with the cancer experience despite its stresses; others may not fare as well. Evidence from this study suggests some options that could improve the cancer care system ■

Satisfaction with family relationships was higher for older people than for younger people, and individuals who had strong perceptions of overall social support had more positive attitudes about their family relationships.

Montana Dept. of Commerce, G. Wunderwald

DISCUSSION AND STUDY RECOMMENDATIONS:
Options For Improving Cancer Care

Because of its vast land area and limited population, Montana, too, is searching for ways of making health care available and accessible to a predominantly rural population.

Lee G. Faulkner

The good news from the medical front is that cancer diagnosis and treatments have improved over the past several decades, resulting in increased survival rates. This medical news is especially good for young people, who will eventually be moving into the ranks of the older generation where cancer is most prevalent. However, this good news is tempered by increased responsibility faced by families who live with cancer. The time spent by individuals with cancer in hospitals and critical care facilities is decreasing, forced by rapid increases in health costs, cost-containment measures, and changes in insurance reimbursement policies. In addition, cancer treatment and rehabilitation improvements call for more complex procedures which are administered over longer periods, adding to family care responsibilities, family costs, and financial hardships. As diagnostic and treatment technologies become more complex, formal cancer care will likely become even more centralized, further limiting the availability of health care services. Consequently, the need for health care provided by family and informal caregivers will increase.

A summary of study findings supports several general recommendations to improve assistance for families living with cancer. How to implement these recommendations and other programs is at the heart of the health care problem in rural regions; consequently, effective alternative methods of delivering assistance must be devised.

Summary of Technical Findings

The findings of this study documented that rural families faced barriers to the availability and accessibility of health care. The study also found that the care of rural individuals with cancer was further complicated by significantly greater severity of other chronic health problems and a greater need for assistance with activities of daily living than their urban counterparts, regardless of age. Because population is so sparse in rural Montana, many health care services are limited and others cannot be supported. Therefore, distances traveled to cancer diagnosis, treatment, and check-ups were found to be extreme for rural families. Rural families also had lower incomes than urban families in the study, which further limited their purchasing power for formal care. However, in one instance rural families had an advantage over urban families—the number of sources of informal care used was significantly greater in rural than in urban areas. These findings were generally consistent with conclusions of other studies of health care in rural regions (40, 41).

Because cancer strikes older people disproportionately, this study documented the relationship of age to the barriers and limitations to care, the needs of individuals with cancer, and the needs of their caregivers. Despite the fact that older individuals with cancer reported a greater severity of chronic health problems and a greater need for aid with daily activities, they reported significantly fewer sources of family and informal assistance.

The findings from this study, however, were only suggestive of possible reasons for the discrepancy between the need for and the receipt of assistance by older individuals. Although the distances traveled for diagnosis and treatment were not related to the ages of individuals, the difficulty of travel may have affected older families more than younger ones. In addition, purchased formal care may be limited for older individuals because their family incomes were significantly lower than those of younger families. Finally, older caregivers reported that they provided less assistance to ill family members than did younger caregivers. Moreover, the greater severity of chronic health problems in older caregivers may possibly have limited their capacity to provide care.

The psychological pressures on both individuals with cancer and caregivers were high, as measured by their depression scores and indicated by their comments. The depression scores of individuals with cancer were higher for those who were seriously ill, had severe chronic health problems or financial difficulties, or had less overall social support. Although higher than a national sample of the general population, the average depression scores of caregivers in Montana were lower than those of individuals with cancer. Finally, although place of residence in Montana was not related to depression scores of either the person with cancer or the caregiver, age was slightly related to depression scores; older caregivers tended to be less depressed than younger caregivers.

Family satisfaction was also unrelated to place of residence, but it was significantly related to age. Older individuals with cancer and their caregivers tended to be more satisfied family members than were younger individuals. Family members who were less depressed were also more satisfied with their families, but information from this study did not indicate whether depression caused family dissatisfaction.

Recommendations

Many states are struggling with the problems of providing health care in rural areas (22). Because of its vast land area and limited population, Montana, too, is searching for ways of making health care available and accessible to a predominantly rural population. The findings of this study suggest several potential changes in the health care system to help families and community members be more effective in providing assistance and in maintaining a quality lifestyle for families living with cancer.

Establish Support Groups

Frequent high depression scores and large numbers of respondents who expressed needs for spiritual and emotional help confirmed that support groups are important. Several family members expressed a strong desire to be part of a support group and felt frustration when none were available. A caregiver said, "While in [treatment], my wife was [in a support group], but as soon as we came home...all support ceased.... My wife and I tried to make contact with a [support] organization, and even tried to get a chapter going, but the distances overwhelmed us...."

Research has shown that support groups help both ill people and their caregivers (18,26,38). Typical support groups assemble in one place to allow people to openly express their feelings with others who have had similar experiences. These groups also allow members to air problems, to get effective solutions to problems, and to have their spirits renewed by sharing with others. However, such groups are difficult to start and maintain in rural regions. Individuals in sparsely populated regions may be too far from one another to assemble on a regular basis, or they may be unable to initiate contact with others in the same community.

However, in one instance rural families had an advantage over urban families—the number of sources of informal care used was significantly greater in rural than in urban areas.

DISCUSSION AND STUDY RECOMMENDATIONS:
Options For Improving Cancer Care

American Cancer Society

However, some efforts in rural areas have been successful. Individuals on home dialysis in Montana, all living 200 to 1,200 miles from the dialysis training center, managed their illness quite well by developing an actively functioning support network, based on help from other patients (34,35). Because support groups are usually community-based, a challenge in rural areas is to find ways of providing such support where distance and lack of organization are major barriers.

Establish Information Centers

The need for information centers was indicated by the number of respondents in the study who wanted information about the management of cancer, services available, and insurance. In Montana, such information is provided by a wide variety of fragmented sources, and the offerings vary from one community to another. For families living with cancer, the information which they need covers an extremely wide range of topics. Some of these informational topics include insurance coverage, details concerning insurance forms and claims, legal and financial matters, as well as detailed medical information about cancer diagnosis, treatment, and medications. However, in order to be effective, an information or referral system must be accessible. It also must be maintained by continual updating and monitoring to ensure the quality and accuracy of the information provided.

Increase Home-Care and Home-Chore Services

The need for community-based home-chore and home-care services in rural areas, especially for older individuals, was indicated in the study results. The higher incidence of chronic illnesses among rural populations, coupled with limited health care services and higher needs for assistance with activities of daily living, make home services important. These home services may be especially vital when both the family caregiver and the ill person have high levels of chronic problems.

The types of home services currently offered in some Montana communities to individuals age 60 and above, on a cost-free basis, are determined at the local level through the Area Agencies on Aging and their local constituencies. Programs and services in each county depend upon budgets and the availability of local labor. For example, programs in some counties cover the expenses of nurse aides and LPNs, while programs in other counties do not. Therefore, free home services that would be helpful to individuals with cancer are available only in counties that choose to offer them, and only to those age 60 and over.

Provide Temporary Accommodations for Patients and Their Families

The need to reduce the costs associated with travel and short-term relocation for treatment was mentioned by individuals in the study. The urgency of this need was confirmed by the long distances traveled for diagnosis and treatment, combined with generally low incomes of older and rural people. As one person remarked, "The families of cancer patients in a state as rural as Montana need special facilities close to larger medical centers where they can stay inexpensively for periods of time to be available to support treatment." In addition, some patients traveled farther then necessary for treatment in order to get it in a location where living costs were less expensive: "Even though it was [520 miles round trip], we had a place to stay [with family] where my wife could stay during the first month after the operations and still be close to the oncologist and surgeon."

In recognition of expenses associated with travel and lodging, a few hospitals and care facilities have ways of accommodating families overnight or for extended stays. Some hospitals have

dedicated rooms for family members, while other hospitals may make referrals to private motels, apartments, and rooms. In Great Falls, The Gift of Life is a special facility designed to accommodate families. In Billings, the Ronald McDonald House provides family housing at a moderate cost. In addition, the Anne Thornton RV Park in Great Falls provides RV hookups for families who must remain in the city for medical treatment.

In communities where special facilities cannot be justified, alternative housing arrangements can be made. Communities may organize a system of referring families and hospital out-patients to private homes or subsidizing lodging at motels and hotels. However, managing the referral system, providing for liability and other types of necessary insurance, maintaining reasonable costs, and establishing standards for cleanliness and comfort are some major problems that communities may encounter.

Provide Incentives Through Public Policies

The study confirmed that care provided by community members is important in the management of cancer in rural areas. Many states recognize that family and informal care is important and that the independence of ill people can be maintained through such care. These states also recognize that increasing the care received by ill family members within the home is one method of containing the ever-increasing governmental expenses of health care (21). The development and use of appropriate public policies may further encourage care of ill individuals by their family members and people in the community. To this end, some states have promoted family and community caregiving through incentives consisting of tax credits for family members who provide caregiving (19).

In addition to tax credits and deductions, Montana could also initiate a system of direct payment to family members who provide care to an ill family member. Agencies in 35 states have, on occasion, permitted payments to people who provide home care to their elderly and ill relatives (21). In addition, local jurisdictions in some states were given authority by state legislation to institute some form of family caregiver payments (21). Montana could also enact legislation requiring that sick leave be granted to family caregivers without loss of jobs and seniority. Such a measure would promote family care and would provide income security to families who are dealing with serious illnesses.

Increase Insurance Coverage

Cancer can be a very expensive disease to diagnose and treat, and a large proportion of the respondents in this study expressed concerns about their health insurance coverage. Health insurance coverage has generally decreased because public and private cost-containment programs have tended to increase deductibles, lower the proportion of allowable expenses reimbursed, and place an upper limit on the amount reimbursable for each procedure. However, while the trend has been to reduce health care coverage, health care costs have continued to increase. Currently, one avenue open to individuals is the purchase of additional health insurance to supplement their existing insurance. The fact that older individuals in the study tended to have less concern about insurance coverage than younger individuals could possibly reflect differences in coverage by Medicare and its supplements as compared to the private insurance policies held by younger people.

The problem of insurance coverage in Montana is greater than was indicated by the respondents in this study because many Montanans do not have health insurance. For example, approximately 20 percent of the Montana population under the age of 65 (141,600) are uninsured (8). Many employers in Montana are too small to have health insurance for their employees, yet insurance provided by employers is the principal source of affordable health insurance. Current proposals being considered in Montana are subsidizing small employers who provide health

The study confirmed that care provided by community members is important in the management of cancer in rural areas.

DISCUSSION AND STUDY RECOMMENDATIONS:
Options For Improving Cancer Care

A combination of community-based services, family education and training , and advanced communications techniques applied to the recommendations of this report can improve cancer care and complement the contribution of family members to the care of their ill members.

insurance for their employees and lowering the minimum coverage that can be purchased for employees. Thus, more employees would have at least some health insurance.

For those people who are not insured, the federal-state Medicaid program is the only alternative when illness strikes. However, this program is available only for qualified low-income and disabled individuals. The Montana Medicaid program covers only 51 percent of the people who are under the poverty income guidelines, while 70 percent are covered nationally (8). Although Medicaid assistance may be available, some who are eligible are not aware of the program and are not referred to it. In addition, some who are eligible, especially individuals in sparsely settled regions, are not in the program because of the difficulties in getting enrolled (36). Enabling individuals to enroll in Medicaid in their own communities rather than only at a county office has been suggested by a national study as one method of increasing the number in the program (36).

Alternative Methods of Delivering Assistance

A fundamental problem in sparsely settled rural regions is finding cost-effective ways of promoting and providing services over wide geographic areas while minimizing cost. Some optional ways of delivering various types of services have been tried in other states; the challenge for Montana is to adapt the best of those approaches and to create new ones. Ideas that have been tested in other states revolved around three concepts: a) community-based services—the mobilization of community volunteers; b) family education and training—a closer coordination of services provided by the formal care system and the services needed by the family; and c) communications technologies—the use of advanced telecommunications.

Community-Based Services

Community-based organizations have been and will likely remain a fundamental method of providing certain types of services to individuals with cancer. For example, in-home care and home-chore services must be provided by individuals at the site; therefore, these services remain essentially community-based, with workers from within the community providing services at reasonable rates. The American Cancer Society programs also depend upon community volunteers for a number of services. However, in some states community-based volunteers are being used to provide training for family members in a wide range of services which include information, support, and counseling.

One such program trained volunteers to teach the following materials: the identification of physical and psychological changes in ill people; effective communication; stress management; elements of personal care for the ill, such as transferring, lifting, bathing, dressing, caring for the hair and mouth, and managing incontinence; the identification of and interaction with community resources; information about health care; and the assessment of caregiver needs (3). Those trained volunteers were expected to teach relatives and friends in their rural communities. That program was replicated in 20 other states (9,10). Such an approach could also be used in community seminars in rural regions or as part of networking systems.

Family Education and Training

Individuals in this study expressed a need for information and training, some of which, because of its technical nature, may require professional instructors. One option is to provide such information and training to family members while the ill person is in a treatment program. This approach would minimize travel time and expense for families. In addition, the use of professional instructors would maintain the high quality of training and information about services such as location, schedule, and cost.

In addition, family members need to know what services are available and how to access them so that they can act as managers of services instead of providing all the care themselves. A project that trained family members as "case managers" concluded that trained family members

undertook more case management tasks than did untrained individuals and that the training was effective (33). The training is especially important for older individuals living with spouses who often have severe health problems which limit the care they can provide. As managers of care services, such families can use their time and energies more effectively by getting care they cannot provide themselves.

Communications Technologies

Innovations in communications technologies have resulted in an "information revolution" in the world, yet such technologies are just beginning to be adapted to the needs of rural regions. Although the conventional approaches of using written materials and classroom teaching will continue to have a place in providing information and instruction, such methods are costly in rural areas. More advanced methods of transmitting information and providing communication among health care professionals, informal care providers, and families could be extremely effective if adapted to rural regions.

Perhaps the most cost-effective way of providing information and other types of assistance to rural people is through advanced telecommunications. Some telephone resources, such as the American Cancer Society's national **HOTLINE, 1-800-ACS-2345**, provide various kinds of information on cancer, referrals, and access to publications. Another hotline, **1-800-4CANCER**, is maintained by the National Cancer Institute. **HOSPICELINK, 1-800-331-1620**, refers individuals to the nearest hospice. Centralized sources such as those can continuously update information and monitor the quality of information being provided.

Telecommunications systems can also be used for a variety of instructional and counseling programs in which professional time and expertise may be used efficiently. Counseling is a serious need among cancer patients and their families, as reflected in the comments of a respondent: "I would have liked to have had much more help in dealing with this, but not much help is available. Untrained people simply do not understand, and neither do family members.... Some type of counseling services should be an integral part of cancer treatment.... I cannot help but believe most people are in critical need of this type of support help." A current project conducted at the University of Washington compares the outcome of "face-to-face" versus "voice-to-voice" counseling to small groups of women who are caregivers for husbands disabled as a result of progressive neurologic disease (6). If "voice-to-voice" counseling proves to be effective, telecommunications systems can deliver effective counseling over distances and alleviate the isolation felt by rural families who live with illnesses such as cancer.

Information and instruction can also be relayed by television through the use of inexpensive cassettes or satellite programming. Perhaps the most advanced use of telecommunications systems is in interactive conferences and classroom instruction, where individuals are in visual and verbal contact with each other. This method has been used effectively in some rural schools where specialized teachers at central locations used interactive television as the instructional vehicle. These interactive television systems could be used effectively for conducting support groups, counseling spiritual and emotional needs, and providing information about cancer, insurance, and legal or financial problems.

A combination of community-based services, family education and training , and advanced communications techniques applied to the recommendations of this report can improve cancer care and complement the contribution of family members to the care of their ill members. Close attention must be given to the needs and experiences of older people who have a high prevalence of cancer and of rural people who have limited access to the health care system. Improvements in cancer care can facilitate the family's ability to manage the disease, to reduce the potential human and material cost, and to maintain a quality lifestyle ■

Establish Support Groups

■

Establish Information Centers

■

Increase Home-care & Home-chore Services

■

Provide Temporary Accomodations for Patients & Their Families

■

Provide Incentives Through Public Policy

LITERATURE CITED

1. American Cancer Society. (1990). Cancer statistics. **Ca-A Journal for Clinicians**, 37, 14-15.

2. American Cancer Society. (1979). **Report on the Social, Economic and Psychological Needs of Cancer Patients in California**. Unpublished Manuscript.

3. Bane, S.D., & Halpert, B.P. (n.d.). **Resource Manual: Information for Caregivers of the Elderly**. Kansas City, Missouri: Center on Aging Studies, University of Missouri-Kansas City.

4. Bowers, B.J. (1987). Intergenerational caregiving: Adult caregivers and their aging parents. **Advanced Nursing Science**, 9, 20-31.

5. Caregiver's toll: Employees run late. (1989, October). **AARP BULLETIN**, 30, 13.

6. Catanzaro, M. (1991). Personal communication. College of Nursing, University of Washington, Seattle, WA.

7. Fitting, M., & Rabins, P. (1985). Men and women: Do they give care differently? **Generations**, 10, 23-26.

8. Frazier, B. (1991). **Health Care for Montanans: Committee Report and Recommendations of Working Committees.** Unpublished report of the Governor's Health Care Committee, Julia Robinson, Chairperson, Helena, Montana.

9. Halpert, B.P. (1988). Volunteer information provider program: A strategy to reach and help rural family caregivers. **The Gerontologist**, 28, 256-259.

10. Halpert, B.P., & Sharp, T.S. (1989). A model to nationally replicate a locally successful rural family caregiver program: The volunteer information provider program. **The Gerontologist,** 29, 561-563.

11. Harpine, C.J., McNeil, J.M. & Lamas, E.J. (1990). The need for personal assistance with everyday activities: Recipients and caregivers. **Current Population Reports**, Household Economic Studies, Series P-70, No. 19. Washington, D.C.: U.S. Bureau of Census.

12. Henry, S.H. (1990). Barriers to access. **Modern Maturity**. Washington, D.C.: American Association of Retired Persons. October/November, 33.

13. Hickey, M. (1986). Problems and successes in rural hospice development. **The American Journal of Hospice Care**, May/June, 37-41.

14. Hinds, C. (1985). The need of families who care for patients with cancer at home: Are we meeting them? **Journal of Advanced Nursing**, 10, 575-581.

15. Hoppe, R. (1990). Poverty severe in nonmetro areas. **Rural Conditions and Trends**, 1(1). Washington, D.C.: Economic Research Service, United States Department of Agriculture.

16. Hoppe, R.A. (1991). **The Role of the Elderly's Income in Rural Development**. Rural Development Research Report No. 80. Washington, D.C.: U.S. Department of Agriculture.

17. Houts, P., Yasko, J., Kahn, B., Schelzel, & Marconi, K. (1986). Unmet psychological, social, and economic needs of persons with cancer in Pennsylvania, **Cancer**, 58, 2355-2361.

18. Ingersol-Dayton, B., Chapman, N., & Neal, M. (1990). A program for caregivers in the workplace. **The Gerontologist**, 30, 126-130.

19. Kane, R.A. (1985). A family caregiving policy: Should we have one? **Generations**, 10, 33-36.

20. Kaye, L.W., & Applegate, J.S. (1990). **Men as Caregivers to the Elderly**. Lexington, MA: Lexington Books D.C. Heath and Company.

21. Linsk, N.L., Keigher, S.M., & Osterbusch, S.E. (1988). States' policies regarding paid family caregiving. **The Gerontologist**, 28, 204-212.

22. McCloskey, A.H., & Luehrs, J. (1990). **State Initiatives to Improve Rural Health Care**. Washington, D.C.: National Governors' Association.

23. Montana Central Tumor Registry. (1988). **Cancer in Montana 1979-1986**. Helena, Mt.: Department of Health and Environmental Sciences.

24. Montana Central Tumor Registry. (1991). Summary report. Unpublished data base 1979-1988. Helena, MT: Montana Department of Health and Environmental Sciences.

25. Montenko, A.K. (1989). The frustrations, gratifications and well-being of dementia caregivers. **The Gerontologist**, 29, 166-172.

26. Montgomery, R.J.V. & Borgatta, E.F. (1989). The effects of alternative support strategies on family caregiving. **The Gerontologist**, 29, 457-464.

27. Moscovice, I. (1989). Strategies for Promoting a Viable Rural Health Care System. **Journal of Rural Health**, 5(3), 216-230.

28. National Governors' Association (1988). **Health Issues in Rural America**. Washington, D.C.: National Governors' Association.

29. Noelker, L.S., & Bass, D.M. (1989). Home care for elderly persons: Linkages between formal and informal caregivers. **Journal of Gerontology: Social Sciences**, 44, S63-70.

30. Opinion Research Corporation. (1989). **A National Survey of Caregivers: Working Caregivers Report**. Washington, D.C.: American Association of Retired Persons.

31. Rosenbaum, E. & Rosenbaum, I. (1980). Principles of home care for the patient with advanced cancer. **Journal of the American Medical Association**, 244, 1484-1487.

32. Sayetta, R. B. & Johnson, D.P. (1980). Basic data on depression symptomatology. In **Basic Data on Depression Symptomatology, United States, 1974-1975**. Series II, No. 216, DHSS, PHS, No. 80-1668. Bethesda, MD: National Center for Health Statistics.

33. Seltzer, M.M., Ivry, J., & Litchfield, L.C. (1987). Family members as case managers: Partnership between the formal and informal support networks. **The Gerontologist**, 27, 722-728.

34. Snyder, T. (1981a). Home care, role of distance to the home training center. Part I. **Contemporary Dialysis**, September, 42-52.

35. Snyder, T. (1981b). Home care, role of distance to the home training center. Part II. **Contemporary Dialysis**, October, 44-47.

36. Summer, L. (1991). **Limited Access: Health Care for the Rural Poor**. Washington, D.C.:Center on Budget and Policy Priorities.

37. Tootle, D. (1990). Nonmetro income growth sluggish. **Rural Conditions and Trends**, 1(1). Washington D.C.: Economic Research Service. United States Department of Agriculture.

38. Toseland, R.W., Rossiter, C.M., & Labrecque, M.S. (1989). The effectiveness of peer-led and professionally led groups to support family caregivers. **The Gerontologist**, 29, 465-471.

39. U.S. Bureau of Census (1989). Projections of the population of the United States 1988 to 2000. **Current Population Reports**, Series P-25, No. 1018; and unpublished preliminary population releases, Montana, 1990. Washington, D.C.: U.S. GPO.

40. Weinert, C. & Long, K. (1990). Rural families and health care: Refining the knowledge base. **Journal of Marriage and Family Review**, 15(1/2), 57-75.

41. Weinert, C. & Long, K. (1987). Understanding the health care needs of rural families. **Journal of Family Relations**, 36, 450-455.

42. Wellish, D., Landsverk, J., Guidera, K. Pasnau, R. & Fawzy, F. (1983). Evaluation of psychosocial problems of the homebound cancer patient: Methodology and problem frequencies. **Psychosomatic Medicine**, 45, 11-21.

American Cancer Society

The American Cancer Society has several assistance programs that local units may initiate in their communities. For purposes of administration and geographic representation, Montana is divided into 71 units. Each unit has volunteer officers and workers, and can select the programs to be offered in the local community from those listed below. Consequently, not all programs are offered in all units.

CANSURMOUNT - Short-term visits to provide functional, emotional and social support from one specially-trained cancer patient to a cancer patient or their family members.

CANSURPALS CANDLELIGHTERS - A support program for young cancer patients and their families.

I CAN COPE - A group program to provide information on cancer treatment, therapy, side effects, nutrition, resource availability and other topics of interest to cancer patients and their families.

LARYNGECTOMY - A short-term visitation program to meet the functional, emotional and social support of laryngectomy patients, in cooperation with the International Association of Laryngectomees.

Clarann Weinert, S.C.

LOOK GOOD . . FEEL BETTER - An informational program to boost self-esteem with grooming information specific to the cancer patient's needs, in conjunction with the Cosmetic, Toiletry & Fragrance Association.

OSTOMY VISITATION - A visitation program to patients by a person who has had an ostomy to assist in the physical & psychological adjustment of ostomy surgery, in cooperation with the United Ostomy Association.

REACH TO RECOVERY - A volunteer trained visitation program to assist the woman before and/or after having surgery for breast cancer, to assist in functional, emotional and social rehabilitation.

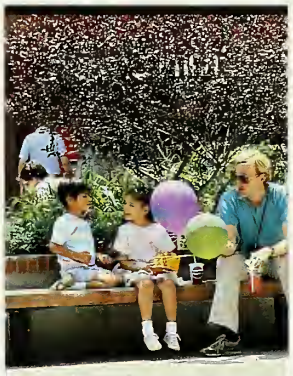
ROAD TO RECOVERY - A program to assist in transportation of the cancer patient to and from treatment.

HOTLINE (1-800-ACS-2345) - A national telephone information and referral system.

RESOURCES, INFORMATION AND GUIDANCE - Responds to inquiries for specific information about cancer, its prevention, diagnosis, treatment and rehabilitation for cancer patients and their families.

GRANTS - Provides $100 maximum per patient, per calendar year for transportation and/or medication expenses. Travel grants for the medically indigent cancer patient to treatment away from their home community is reimbursed at the rate of ten cents per mile. Payment for palliative drugs as prescribed by a licensed physician will be paid directly to the cancer patient after he/she has submitted receipts. The medication must be listed on the ACS Approved Drug List to receive reimbursement.

LOAN CLOSET - Provides health care equipment on a loan basis for use in the home to contribute to the care and comfort of the cancer patient. Equipment includes beds, wheelchairs, walkers, commodes, etc.



Marci Catanzaro

MONTANA
STATE
UNIVERSITY
1893•CENTENNIAL•1993